

**Annex 1** List of priorities to convert in actions for the entire care trajectory

**Transversal** (15 actions)

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Patients and caregivers need psychological support  
Patients and caregivers need to be heard  
Patients and caregivers need information delivered in plain language as well as guidance and support  
Professionals must be well trained  
Professionals must be knowledgeable  
Professionals must be able to empathize with patients  
Caregivers need support  
Patients and caregivers need more information about available resources; families need guidance  
Patients need support for losses occurring throughout the course of disease  
Patients need to be empowered  
Family members need to be able to communicate with professionals without the presence of the patient  
Communication between hospital professionals and families must be improved  
Good interpersonal treatment and manners are important for perceived quality  
Caregivers need more support  
Caregivers need good information

**Detection of high needs** (2 actions)

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The patient should feel accompanied during diagnosis and explanations  
Caregivers should receive the right amount of information (neither too much, nor too little)

**Follow-up care plan** (18 actions)

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Caregivers need rapid, home-based solutions about attending family members (advice, tips, strategies)  
Patients prefer the assigned professionals, even if they have to wait  
Nursing and medical care and follow-up at home are deeply appreciated  
Hospital and primary care professionals need to coordinate closely  
Patients need help at home (financial support for caregivers, volunteers)  
Steps should be taken to avoid sending patients to nursing homes  
Family members need breaks from caring for patients  
Social work must be systematized  
Caregivers need courses about how to provide care  
Caregivers groups should be created for patients; there should be open sessions where family members can express their needs  
There needs to be a programme of activities for families  
Care must be coordinated with the hospital: outpatient visits must not be cancelled without advance notification  
Information, advice, recommendations, and guidelines should be provided in writing  
Early identification and communication of symptoms strategies should be available for patients and caregivers  
Patients' home must be adapted to their special needs and limited mobility  
Patients should have the appropriate technology, including GPS tracking  
Caregivers should have a way out  
Caregivers should have sufficient resources to attend patients as their disease progresses

**Crises management** (4 actions)

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The system should avoid unnecessary trips to the hospital  
Patients prefer hospital care during crises because treatments are done there  
Patients prefer to be attended at home during crises, provided the treatment is the same in both places

55 Patients need to have a 24-hour hotline where they can consult professionals and solicit help at home  
56 if necessary  
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58 **Transitional care (18 actions)**

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60 Hospital, primary care, and home-based care must be coordinated  
61 Patients must have the technical support they need to return home after hospitalization  
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63 **End-of-life care (6 actions)**

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64 Support groups should be created to facilitate mourning  
65 Family members/caregivers have no preferences for the place where end-of-life takes place: wherever  
66 the patient is most comfortable and his or her needs are met best  
67 It is essential to avoid suffering at the end of life  
68 Patients prefer to be admitted to nursing homes than to become a burden for the family  
69 Patients prefer to die at home  
70 Professionals should take actions to get to know the patient and family before the end of life